



# Early Childhood Policy Council Parent Advisory Committee Meeting

## Summary Report

Wednesday, August 31, 2022: 10:00 a.m. – 12:00 p.m.

### Physical Meeting Information:

- 1000 G Street, Sacramento, CA 95814 WestEd, 5<sup>th</sup> floor, Capitol Room

### Agenda

#### 1. Welcome

- Welcome
- Public comment

#### 2. Supporting Children with Special Needs and Their Families

- Committee discussion
- Public comment

#### 3. Adjourn

### Attendance:

- **ECPC Parent Advisory Committee Members:** Mary Ignatius, Cherie Shroeder, Deborah Corley-Marzett, Naima Facih, Patrick MacFarlane, Yenni Rivera
- **ECPC Workforce Advisory Committee Member:** AnnLouise Bonnitto
- **ECPC Council Members:** Carola Oliva-Olson, Kim Johnson, Lupe Jaime-Mileham
- **Presenters/Speakers:** Brian Winfeld, Jill Boxer, Lori Banales, Maricris Acon, Rose Chacana
- **Support Staff:** Karin Bloomer, David Burchiel, Gina Morimoto, Margarete Lee
- **Interpreters:** Giovanna Wormsbecker, Diana Orozco, Sarah Sun, Yan-Nan Chou

## **Summary Report**

### **Mary Ignatius, ECPC Parent Advisory Committee Chair**

Mary Ignatius, chair of the Early Childhood Policy Council Parent Advisory Committee, opened the meeting by welcoming online and in-person attendees and thanking everyone for their commitment to serving the ECPC. Ms. Ignatius expressed her expectation that the Parent Voices platform would provide informative and interesting stories during the meeting. She then introduced ECPC Parent Advisory Committee Members Yenni Rivera and Naima Facih and asked them to respond to the following prompt: “Thinking back to your experience when your children were in their youngest years and you were learning about the unique needs that were coming up for them—we know that you faced many challenges, but for this moment if you could focus on one of those challenges—and now that you can look back, what do you think would have solved that challenge for you? What resources or supports did you need so that the families who are coming after you can have a smoother experience?”

#### **Yenni Rivera:**

Ms. Rivera said that the main thing for her was access to the services. Ms. Rivera shared that while recovering from trauma sustained as a domestic violence survivor, she realized her son needed many of the same supports she was receiving. However, she struggled to access services for him: “I’m already trying to take care of anxiety for myself, and here I am trying to see, ‘where can I connect my son?’ I think it’s that access, the limited access. Mind you, my doctor had connected me to a children’s hospital in Los Angeles—a big, big hospital with a lot of resources—but there was a wait list that, for us, it took about a couple of years, two years.”

Ms. Rivera also said that having Medi-Cal delayed services, because it can take up to six months before a referral is approved. She tried approaching various facilities, but the only service she was able to receive for her son was diagnostic testing: “Again, they let me know the diagnosis had to do with mental [health], but they didn’t have any resources. Basically, I got a paper that said, ‘This is what he has,’ twice, ‘but good luck, go find it. I hope you get connected somewhere.’ So here I go again, trying to find a family crisis center.”

While Ms. Rivera was able to find a family crisis center, it then took a year to obtain therapy for her son through the center’s resources. She described how she had to do all the work looking for services and researching how to support her child while still recovering. Ms. Rivera described how parents with low incomes endure frustration and how that affects them: “I’m here to speak for those parents that have to advocate. Let me tell you, some parents give up along the way. Some parents get so frustrated that their children don’t get help, and then you wonder why. Well, this is why. Some parents don’t even get connected until years later when their sons and their children, their daughters, are already behind, so we have to take into consideration the access that we

provide and shorten those wait lists. There are a lot of children out there waiting right now to be connected to mental health resources, and the problem is that mental health does affect your learning.”

**Naima Facih:**

Speaking after Ms. Rivera, Ms. Facih shared the journey of her son, who was born 16 weeks preterm and weighed one-and-a-half pounds. For the first few years of her son’s life, Ms. Facih received services through the Regional Center of the East Bay, and an occupational therapist, physical therapist, nutritionist, and speech therapist made weekly home visits. But when her son was three, Ms. Facih moved to San Francisco. She spoke to the Regional Center about her son’s services and was told that at age three, services had to be managed through the San Francisco Unified School District. Ms. Facih reached out to the district, which agreed to continue the same services but would only provide one hour per week for each interventionist. Ms. Facih tried to convince them that this was not enough: “I kept communicating with them. I kept talking to them and telling them, ‘That’s not enough for my son. I feel like he’s going to be behind because all the cognitive and physical development happens between zero and five. How come you discontinued his service at the age of three?’ And they said, ‘That’s all that we can provide.’ The explanation from the school district was that there were no finances for more support.”

Ms. Facih said that she had to accept that, however, she decided to try to provide the support by herself and went back to school to study child development.

When her son was six, the school district conducted a new assessment and determined the only service he needed was 45 minutes of occupational therapy once a week. Ms. Facih noted that her son is an example of a child with needs not receiving necessary support: “I did my best to support my son in all the areas, but what I want to say [is that] it’s not happening only to me. I know it happens to most parents with kids with special needs. This is just a lack of support. And the lack of resources for these parents makes it very, very hard to move forward.”

Ms. Ignatius thanked both Ms. Rivera and Ms. Facih for sharing their stories and struggles and expressed her hope that they would receive more support from the Department of Developmental Services (DDS). After this, she introduced guest presenters from the Department.

**Brian Winfield, Chief Deputy Director, Department of Developmental Services**

Mr. Winfield was joined by other representatives of DDS for a presentation that addressed several key issues:

- How parents can get information about their child's development, developmental services, and what kinds of resources might be available when they have concerns
- How the referral and intake processes work with regional centers
- How to navigate the different systems that might play a part in children's development and progress throughout their lives
- What resources and opportunities for learning and engagement exist for families

Mr. Winfield noted that the [DDS homepage](#) has many useful resources for parents who might have questions about their children's development. These include milestone checklists, which families can refer to if they are concerned about their own children's progress, and Reasons for Concerns, a brochure that identifies common risk factors and signs of developmental delays and challenges. Mr. Winfield also noted that DDS does its best to distribute all the available information throughout the community, especially to daycare centers and physicians.

Mr. Winfield gave an update on the development of informational packets, as included in the 2021 budget. Packets are currently under development for Early Start services and Lanterman Act services and will be available through DDS and all 21 regional centers. The packets will provide parents, family members, and other stakeholders with basic information about the developmental services system, services that are available, and what to expect.

Mr. Winfield also talked about the regional services associated with the DDS. In total, the department maintains 21 regional center contracts with private nonprofit agencies located throughout the state. DDS has oversight of the regional centers and bears the responsibility of ensuring services are available to consumers and families. The regional centers coordinate and fund a host of life-long services, provide community outreach and education, and assist families with accessing resources. They also provide monitoring and oversight of services.

### **Jill Boxler, Early Start Client Services Manager at Alta California Regional Center**

The presentation continued with Ms. Boxler discussing the Early Start program and how the regional center operates.

All regional centers have similar intake processes. While referrals typically come from a parent, pediatrician, or hospital, the law also allows referrals from a grandparent, child care provider, or Early Head Start teacher. Referrals can be made via phone call, email, or the regional center's website. The regional center always checks in with the parent or caregiver to ensure they are aware of the referral. After that, there is a 45-day timeline for the completion of the intake, which includes a multidisciplinary assessment. To gain a complete picture of the child's circumstances and needs, the service coordinator will also conduct a family assessment that includes an in-depth conversation with the parent

or caregiver about their concerns, priorities, and resources. A child's eligibility for services is determined based on whether they meet one or more of the necessary criteria:

- Identified developmental delay in cognitive, physical, social-emotional, or adaptive skills
- Established risk condition of known etiology (e.g., a diagnosed medical condition or genetic disorder)
- High risk circumstance, such as premature birth or a parent with developmental disability

Ms. Boxler also provided an overview of the services regional centers can provide—physical therapy, occupational therapy, speech therapy, behavioral interventions, and connecting parents to supports through other community partners—before turning the presentation back over to Mr. Winfield.

### **Brian Winfield, Chief Deputy Director of the Department of Developmental Services**

In the next segment of the presentation, Mr. Winfield explained the overlapping systems involved in regional centers' ability to serve children. From birth to two years, children are part of the Early Start program, and they have access to Part C services. At three years of age, they become eligible for Part B services. Children ages three and four years have access to Provisional Lanterman services, which differ from Lanterman Act services. As Mr. Winfield explained, they introduced Provisional Eligibility in 2021 to bridge Early Start and Lanterman services for some children. "If a child is in Early Start and they're aging out, the regional center will assess them for a developmental disability, which would then entitle them to ongoing Lanterman Act services. But if they don't qualify by that definition, then they will assess them for Provisional Eligibility to continue to work with the individual and family. Then there is a reassessment at age five to see if they have a developmental disability at that point or if those additional services have assisted them enough that they don't need lifelong services."

Mr. Winfield then passed the presentation to Rose Chacana.

### **Rose Chacana, Director of Koch Young Resource Center**

Ms. Chacana explained that Family Resource Centers (FRCs) were created under the Early Start Act to support families that have children with special needs. The mission of the FRCs is to promote, increase, and share resources that are available in the community, and most of today's FRCs serve families with children of all ages. FRCs are places where parents can connect with other parents who share similar concerns. FRCs also allow parents to speak to informed staff about a child's diagnosis, navigating the special needs system, locating community resources, and issues related to referrals.

Parent-to-parent support is one of the most important elements of FRCs. This support varies based on parents' comfort level and can include a peer support partner, a mentor who can be matched with a parent, or participation in parent support groups, which are more informal.

Ms. Chacana also talked about the different ways FRCs disseminate information: "This is the way that we provide information either online, on our websites, social media platforms, as well as it can be done in person or telephone, email. We do our email bulletins regularly. We send announcements out daily, and that's how we continue to connect with our community in terms of what's coming up or what's available."

FRCs also support families by assisting them in navigating and understanding the process of accessing services. They provide new family orientations, which allow families to get to know the regional center system, as well as how special needs agencies work together.

Ms. Chacana also talked about the active role FRCs had in supporting struggling families during the pandemic: "[M]any of the FRCs stepped up and worked closely with community partners to distribute much-needed basic needs such as food, diapers, developmental supplies for the babies, backpacks, clothes, toys, etc."

As a final note, Ms. Chacana added that what is most important about FRCs is that the combination of support services and one-to-one parents support helps families understand they are not alone: "Professional support, of course, is essential, but that parent-to-parent connection is the most important thing that a parent can know, that they're not alone, that someone is there to help them."

### **Discussion and Comments Panel**

After the DDS presentation, the floor was opened for comments and discussion by attendees. Ms. Ignatius began the discussion with a question regarding situations when parents go through the service referral system but ultimately don't receive services due to ineligibility. Brian Winfield responded to the question: "The department is developing an ombudsperson office that will be a resource for families. If an individual or a family is having difficulty, I would encourage them to speak to the service coordinator. If that's not effective, then asking to speak with the supervisor at the regional center and continuing to elevate that concern until the family feels that they've been heard or they have the information that they need to resolve the issue."

Cherie Shroeder from Foster Families of California raised a concern that foster families sometimes struggle to get Early Start assessments, even though children who have been exposed to drugs qualify for the Early Start program. The DDS representatives confirmed that these children are eligible for Early Start services. Ms. Shroeder also noted that many foster families are not aware of this: "Almost all our children should be able to qualify, yet I don't think everybody always knows that. We do try to tell people

that in our preapproval classes, though I don't know if somewhere the ball gets dropped. It's just a struggle, for whatever reason, a struggle to get those services sometimes.”

Naima Facih raised the issue of maintaining connections with families after their children age out of Individual Family Service Plans at three years old: “Just in my case, I still have the connection with the regional center, but unfortunately, the services that they're providing for families and children are not available. For these services, they provided 15 hours for after school or during school hours to support my child. Some services are available, but in the meantime, there are no resources [to provide the services]. For example, there is no respite available. There are no respite agencies that we can call... Sometimes they don't mention to me what's available, and I have to ask for it. And I feel like it's happening right now. It's not something that happened a long time ago. This is what I'm dealing with right now with the regional center. They have services available for families, but there are no resources that how I'm going to get this service.”

Mr. Winfield responded to Ms. Facih saying that the nationwide shortage of direct service workers affects the availability of services. He added that the department is implementing several initiatives to help shore up, improve, or increase the direct service workforce. Alternatively, if there isn't a worker, for example with the respite agency, there are participant-directed services: “[M]aybe you have a family member or a friend—someone that you trust—who would provide that service, and the regional center can fund it that way. We've heard from many families that they would much prefer to have a family member or a friend provide that service as opposed to someone they don't know.”

Blake Hofstad from Parent Voices talked about the issue of local education agencies evaluating four-year-old children for Individualized Education Programs but denying services for families whose children are currently enrolled in a family child care center or Title V preschool rather than transitional kindergarten program: “I wanted to flag this because this is a huge issue impacting a parent's ability to choose an early child care environment that best suits the child's and the family's needs. They're being faced with an impossible choice. Maybe they don't want to choose to put their child in transitional kindergarten, which is their right, but because they have a child with special needs, they're being denied those essential services that their child needs to start kindergarten on track.”

For the final notes, the chair of the committee shared information about parent engagement surveys from Parent Voices. The first was about their experiences accessing services through the Department of Social Services, and the second related to families' experiences accessing services for children from birth to age six. The chair also mentioned that AB 92, which would permanently eliminate family fees for families earning under 75% of the state median income, has gone to the governor's desk. She

also discussed the upcoming ECPC events and thanked everyone for participating in these conversations. The meeting was adjourned after her remarks.